



New Wellness Program Rules Undermine Patient Privacy and Protections

Employees will be faced with a difficult choice—either disclose personal health information or maintain their privacy and pay more for health coverage

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New rules issued by the U.S. Equal Employment Opportunity Commission (EEOC) weaken protections against invasion of medical privacy and significantly weaken workplace and health insurance discrimination safeguards afforded by the Americans with Disabilities Act ([ADA](#)) and Genetic Information Nondiscrimination Act ([GINA](#)).

FORCE played an active role in GINA's passage in 2008. The law prohibits group health plans and insurers from denying coverage to healthy individuals or charging that person higher premiums based solely on a genetic predisposition to developing a disease. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions.

A key element of GINA and ADA is that they prohibit employees and their families from being coerced into sharing sensitive medical or genetic information with their employer. For GINA, genetic information encompasses not only an employee's genetic test results but also their family members' medical histories. The law clearly includes spouse medical histories to prevent employers from discriminating against employees due to the potential costs of health care for their spouse.

ADA and GINA permit employer-sponsored wellness programs to request medical or genetic information, but mandate that employee participation in such programs be voluntary. The new rules, however, allow employers to charge significantly higher health insurance premiums for employees who wish to keep health information about themselves or their spouses private. For health plans that cover the employee and his or her spouse, the employee could be required to pay a 30% penalty per person, up to of the cost of self-only coverage. The average cost of an individual health plan is \$6,251 per year. As such, the new rules allow employers to impose a total annual penalty (defined as a "limited inducement" by the EEOC) of up to \$3,750 for an employee and spouse if they choose not to partake in the wellness program.

Many wellness programs include a Health Risk Assessment (HRA) and/or medical exams that are not job-related. Under the new rules, the medical questions and tests imposed by an employer's wellness program are considered voluntary—even if workers are subjected to thousands of dollars of penalties for not participating. FORCE and many other patient advocacy groups believe that employees will feel that they have no choice but to take part as many cannot afford thousands of additional dollars in health care premiums.

Encouraging health and wellness seems like a worthwhile endeavor. Yet, there is significant debate about whether wellness programs result in the promised benefits of improved health and reduced healthcare costs. The scope and quality of these programs vary widely. The EEOC established no minimum standards for wellness programs except that they must be “reasonably designed to promote health or prevent disease.” Who determines what constitutes a reasonable design?

The new inducements will apply to future employer-sponsored wellness programs beginning on or after January 1, 2017. The EEOC asserts that “The absolute prohibition on the use of genetic information to make employment decisions...remains intact, as do the existing protections of Title I of the ADA, which prohibits discrimination on the basis of disability.”

These regulatory changes are short-sighted and cast a negative light when our nation is embarking upon the largest research initiative ever attempted—the Precision Medicine Initiative (PMI). With this in mind, we should be strengthening protections of medical and genetic information instead of implementing policies that diminish faith in health privacy and confidentiality. People may opt not to participate in PMI and other medical research out of fear that they will be pressured into reporting these results to their employers' wellness programs.

FORCE applauds the expanded access to health insurance and coverage of preventive services brought about by passage of the Affordable Care Act (ACA); which has benefited the hereditary cancer community. The ACA's inclusion of wellness programs has great potential but ultimately may fail to protect people's health due to this approval of punitive measures to “incentivize” participation and loopholes that will invite potential discrimination.

While disappointed with the weakened rules and protections, FORCE will continue our efforts to represent the interests of the hereditary cancer community. We will ensure that individuals and families at increased risk of cancer understand their rights and how to protect themselves against discrimination. Looking forward, we will advocate for better approaches to promoting health and fitness to the American population that do not infringe on the rights of members of our community.

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